

RYAN WHITE: A GEOSPATIAL ANALYSIS OF HIS CORRESPONDENCE

Haley Lynn Shaeffer

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Master's Thesis Committee

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Daniel Johnson, PhD, Chair

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Jeffrey Wilson, PhD

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Vijay Lulla, PhD

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Haley Lynn Shaeffer

## RYAN WHITE: A GEOSPATIAL ANALYSIS OF HIS CORRESPONDENCE

The letters Ryan White received over the course of his diagnosis, illness, and eventual death show a spatial distribution that reflected the United States' response to Ryan's condition. Ryan was diagnosed with AIDS in December of 1984 at the height of the epidemic, and the panic that surrounded it. In 2000, the Children's Museum of Indianapolis accessioned a selection of letters sent to Ryan White and his mother, from 1980 to 1993. The expanded incorporation of these letters into the museum's "Power of Children" gallery will introduce museum visitors to the public view on Ryan and the role he played in developing the public perception and awareness of AIDS in the 1980's.

Originally, it was anticipated that the distribution and number of letters Ryan received directly related to the concentration and spread of AIDS cases around the US. This research assumed that the AIDS community would have been more supportive and empathetic of Ryan's diagnosis, resulting in those populations sending a higher number of letters. This assumption was also informed by the fact that the highest number of AIDS cases were in areas with large populations such as New York City, Los Angeles, and Miami. Yet findings showed relatively few letters were coming from the populated coasts where AIDS was more prevalent, and many more letters than expected came from areas with lower populations across the US.

Ryan was one of the first children to go public with his AIDS diagnosis, which sparked strong reactions among people throughout the United States. Ryan's correspondence and the outpouring of support he received allows insight into the

multifaceted reaction to the AIDS crisis, especially from young people. Before Ryan became associated with the AIDS epidemic, this disease was seen primarily as an urban, gay, and drug-user related issue. The goal of this research is to gain further understanding of society's shifting response to Ryan and AIDS during the 1980's, by placing these letters in their social and geographic context.

Daniel Johnson, PhD, Chair

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## LIST OF ABBREVIATIONS

AIDS	–	Acquired Immunodeficiency Syndrome
HIV	–	Human Immunodeficiency Virus
CDC	–	Center for Disease Control
IV	–	Intravenous
GRID	–	Gay Related Immunodeficiency Disease
AID	–	Acquired Immunodeficiency Disease
STD	–	Sexually Transmitted Disease
CARE Act	–	Comprehensive AIDS Resources Emergency Act
IUPUI	–	Indiana University-Purdue University of Indianapolis
GIS	–	Geographic Information System
SQL	–	Structured Query Language
CBSA	–	Core Based Statistical Area
KDE	–	Kernel Density Estimation

## INTRODUCTION

Ryan White was born on December 6, 1971 with hemophilia, a disease which required blood transfusions throughout his life. One of these blood transfusions was what eventually led to him contracting Acquired Immunodeficiency Syndrome (AIDS) (White & Cunningham, 1992). Ryan was diagnosed with AIDS in December of 1984, at the height of the epidemic and the moral and social panic that surrounded it. He was one of the first children in the United States to share that he was diagnosed with AIDS, and his engagement with the public launched a new outlook on the disease (Health Resources & Services Administration, 2016). In 1989, Ryan White stated, “Let’s make it (AIDS) a disease and not a dirty word” in response to people questioning making his story public with the ABC TV movie, *The Ryan White Story* (Aldridge, 2014). Using this idea Ryan helped spread awareness, which allowed people throughout the United States see AIDS in a new light, it was no longer just a “gay disease” – it could affect anyone.

Ryan White received an unknown number of letters from people across the world after his diagnosis was made public. His mother saved just under 5,400 letters. The collection of letters ranged from fan mail and responses to media coverage, to hate mail and ideas for cures. Examining where the letters were sent from informs the understanding of how the public reacted to Ryan and the events in his life. In 2000, the Children’s Museum of Indianapolis accessioned a selection of 5,379 letters that were sent to Ryan White mostly between 1989 and 1990. These letters were given to the museum by Ryan’s mother as a part of the larger collection. Originally, only a handful of letters were used in a gallery display, the rest were stored for future use. The expanded incorporation of these letters into the museum’s “Power of Children” gallery will

introduce museum visitors to Ryan's role in developing the public perception and awareness of AIDS in the 1980's. Ryan received letters from every state in the US and many countries throughout the world. Examining the letters Ryan received allows for an interpretation of the way in which he and his situation were perceived by the public. One poll released in 1988 suggested that the sympathy the public feels for people with AIDS did not extend to gay men and intravenous drug-users (Kagay). Ryan and children like him, afflicted with AIDS were often looked at very differently by the general public, typically with more support and sympathy. This research provides new ways to interpret the United States' response to Ryan's case during the 1980's and early 1990's. The goal of this research is to gain further understanding of society's shifting response to Ryan and AIDS during the 1980's, by placing these letters in their context using a geographical investigation, temporal analysis, and a density examination.

## **BACKGROUND**

When Ryan was diagnosed with AIDS, very little was known about the disease. Researchers were quickly gaining knowledge on AIDS and its transmission but most people weren't sure how it spread or who could get it, and the outlook was typically grim for anyone who contracted the disease. This led to a fear of the people who acquired AIDS and, more generally, social groups associated with the disease including gay men and intravenous (IV) drug users. In December of 1984, there still was no commercial blood test for human immunodeficiency virus (HIV), the virus discovered to cause AIDS. An AIDS diagnosis was based on symptoms alone (U.S. Department of Health and Human Services, 2018). Many questions had yet to be answered - Could you contract AIDS from shaking hands with someone? Kissing? To what extent do bodily fluids have to mix? These questions were fraught with fear and anxiety, which caused difficulties for some of the most at-risk groups.

After his diagnosis in December of 1984, Ryan did not return to school. Then in spring of 1985, when Ryan began to feel better, his mother, Jeanne, called to see if Ryan could return to school for a visit. The Superintendent denied Jeanne's request, and this began a long battle with the Kokomo School District. In August of 1985, when Ryan would have been an incoming seventh grader, the school was still refusing to admit him (White & Cunningham, 1992). The Superintendent James Smith was quoted in an article in the Kokomo Tribune stating, "He based his decision on the 'unknowns and uncertainties (about AIDS) and the inherent fear that would generate among classmates. We are obligated to provide an education for the child.' Smith added, explaining Ryan 'will have to receive instruction at home'" (MacNeil, 1985, para. 14). It wasn't just the

school administration that wanted to keep Ryan out of school. Parents of Kokomo students signed 117 claim forms threatening civil suits if Ryan was allowed to return to school and approximately fifty teachers voted to keep him out of school. The Indiana Department of Education ruled that Ryan could return to school as long as he was deemed fit to return by the Howard County Health Officer, but this was appealed by the Kokomo School Board. It wasn't until February, 1986 that Ryan was allowed to return to school for the first time.

On his first day back, 151 of the 360 students at the school stayed home and seven transferred to new schools (White & Cunningham, 1992). That same day, a Howard County Judge filed a restraining order on the behalf of Concerned Citizens and Parents of Western School, which again barred Ryan from school. The battle continued and eventually, the Indiana Court of Appeals and the Howard County Health Department deemed that Ryan was permitted to return to school. He began his eighth grade year at Western Middle school in August of 1986. The school put extreme restrictions on his activities such as requiring him to use disposable utensils, separate bathrooms, and excluding him from gym class activities. In May of 1987, after Ryan's eighth grade year, the White family moved from Kokomo, IN to Cicero, IN. In August of 1987, Ryan attended his first day at Hamilton Heights High School without protest from students, teachers, or administrators. This was a progressive view and was featured on the cover of USA Today (White & Cunningham, 1992). The battle with the Howard County School District was an important factor in prompting Ryan's outreach work to spread awareness about AIDS.

Understanding the climate that surrounded AIDS in the 1980s and 1990s is valuable for understanding the letters Ryan was sent. In her book *Inventing AIDS*, Cindy Patton (1990) discussed how the AIDS epidemic was viewed in such a negative light by the general public. Patton goes so far as to say it was seen as a biomedical experiment or holocaust by some. It was also called a 'plague' which resulted in widespread fear of AIDS and the unknowns that surrounded the disease (Donovan, 1993). This fear extended to the most at risk members of society; people not only feared AIDS but the people most commonly associated with it.

### THE FIRST YEARS OF THE AIDS EPIDEMIC

In 1981, the first signs of AIDS were mentioned in the *Morbidity and Mortality Weekly Report*, published by the Center for Disease Control (CDC). At that time, scientists were noting cases across the United States of gay men dying, due to aggressive and rare diseases. One of these diseases was *Pneumocystis carinii* Pneumonia, a type of pneumonia that typically occurs in immunosuppressed patients (CDC, 1981). In 1982 the first reference to the disease that would eventually be named AIDS was mentioned. It was called GRID, or Gay Related Immunodeficiency Disease or AID, Acquired Immunodeficiency Disease. The name GRID was used, because the first reported cases of the disease were limited to the gay male population. It was not until later in 1982 the name was changed to AIDS or Acquired Immunodeficiency Syndrome, when doctors realized that the disease was not limited to just gay men (Altman, L. K., 1982). As the idea that AIDS was a disease seen in primarily gay males shifted, the blame shifted to



also include urban, low income people of color. Patton (1990) identified the difficulties that came with this shift in attitude by calling it the ‘degaying’ of AIDS. The ‘degaying’ of AIDS was the first step in changing how AIDS was talked about by the broader public. Ryan was one of the first children to publicize the fact that he was living with AIDS, which contributed to it becoming more than just a gay disease (White-Ginder, ND). Once this stigma was lessened, the idea of AIDS as an urban and drug-user related issue permeated throughout the United States and an increase of fears related to race and class increased dramatically (Patton, 1990). Still, AIDS was not a disease that was talked about as being a white, rural, middle-class American problem.

### THE UNKNOWN SURROUNDING AIDS

It wasn’t until September 24, 1982 that doctors had a definition for AIDS, “a disease at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known case for diminished resistance to that disease” (CDC, 1982, para 7). Fear of the disease grew throughout the early 1980s, due to misinformation and lack of understanding that perpetuated these fears.

People diagnosed with AIDS struggled to keep jobs, secure housing, and obtain social support. Oftentimes this was due to the way AIDS victims were viewed, it wasn’t just the disease that was feared, but also the people diagnosed with it (Brandt, 1986). Dennis Altman (1986) in his book *AIDS in the Mind of America*, discusses how the Reagan administration’s response to AIDS, perpetuated the idea that gay men were to blame for the AIDS epidemic. One of the ideas proposed by the administration was the quarantining and firing of gay men (Altman, D., 1986). People didn’t understand how the

disease was spread and it was this initial fear mongering that began the ostracism of the two groups of people most commonly associated with AIDS at this time, gay men and intravenous drug users.

In 1983, the September 9<sup>th</sup> issue of the *Morbidity and Mortality Weekly Report* published by the CDC detailed the major transmission routes for AIDS and declared the disease could not be spread through casual contact. This was a major shift in the AIDS epidemic, since before this announcement people were unsure of how the disease was moving from person to person. Still, the public was reluctant about the disease and its potential transmission. Patton (1990) described the ‘Heterosexual AIDS Panic’ as a shift in the idea of safe sex, from one of heterosexual sex being “safe” to the idea that abstinence, monogamy, and condoms were the only ways to be safe after the rise of AIDS. This began an in-depth discussion on what constituted safe sex and why it is important for everyone to practice, no matter sexual orientation. “The Condom in the Age of AIDS” by Deborah Lupton (1994) discussed how condoms were viewed in the 1980’s. She explained that the condom was seen in a negative light, since it was typically associated with Sexually Transmitted Diseases (STDs) and “traditionally worn in encounters with prostitutes,” thus it was seen as a symbol of immorality and deviance (p. 304). Understanding why condoms were viewed negatively and how they affected the idea of safe sex, lets us grasp why condoms were slow to be used and why AIDS continued to spread rapidly. The stigma associated with AIDS also extended to intravenous drug users, when discussing the idea of being ‘safe’ in the age of AIDS.

The lack of education, slow spread of information and awareness, and fear of the disease led to a sluggish response to AIDS federally. This slow response influenced the

public's reaction and the quick spread of the disease. Patton (1990) explained that during the initial years of epidemic, not enough was done to inform and help those most at risk. So much of the response to AIDS was hidden from public view, which caused a deepening of the stereotypes against the people most at risk. The slow governmental response and the lack of risk education for the public allowed AIDS to spread and the problem to grow exponentially. Aran Ron and David Rogers (1989) in their article "AIDS in the United States," discussed how the media often plays a large part in how quickly the government responds to crises. Examining the relation between the governmental response to AIDS and how the disease continued to spread is important for understanding how and why large amounts of misinformation permeated throughout the US.

## THE DEFINITION OF AIDS

In 1985, two major actions were taken for the response to the AIDS epidemic. First, the definition of AIDS was revised by the CDC. The revised definition of AIDS gave a clearer picture about how and when HIV, the virus that causes AIDS, shifted to AIDS within the body. Second, the first commercial blood test was made available to detect HIV antibodies in the blood. The commercial blood test detected HIV antibodies in the blood, which allowed for the patient to be diagnosed with HIV before becoming symptomatic (HIV.gov, 2019). This allowed for more accurate reporting by medical facilities across the country. Patton (1990) explained that when the blood test for HIV came out, it was used as a means to determine who did and did not need to practice safe sex. This perception caused more problems by legitimizing unprotected sex with the

individuals deemed 'safe' and led to a continued spread of AIDS, this also furthered the idea that there were 'safe' and 'dangerous' people. Oftentimes, being gay or a drug-user was seen as deviant or dangerous behavior. Donovan (1993) explained that this caused groups of people to be lumped into categories of 'deserving or underserving' of government support (p. 6). Along with deserving and underserving categories, the idea of safe and unsafe groups evolved. The safe groups were often women, children, hemophiliacs, and blood transfusion recipients. Safe groups were seen as people who did not partake in deviant behavior, so they were either not at risk or not to blame for their disease. The two most common unsafe groups were gay men and intravenous drug users. This perception led to a harsh dichotomy between the most at risk populations, and the population that deemed themselves 'safe.' Dorothy Nelkin, in her article "AIDS in the New Media" (1991) discussed how the press labeled AIDS as an STD, instead of a viral disease transmitted by blood and other bodily fluids, much like hepatitis. This reinforced the idea that AIDS was caused by deviant and unsafe behavior. Even in 1985, people were still reluctant to accept the ruling made by the CDC that AIDS could not be transferred by casual contact. A CBS poll published in *The New York Times* detailed that just under half of the Americans surveyed believed that AIDS could be transmitted by sharing a drinking glass, just over a quarter believed that toilet seats could spread the disease, and a third believed even being around those with AIDS could result in transmission of the disease (Brandt, 1986). Talking about AIDS as an STD and as a disease only those who are 'deviant or dangerous' could contract, permeated the issues facing those who were diagnosed with AIDS or considered to be in an at risk group. It

also led to a spread of the disease throughout the groups of people who deemed themselves ‘safe.’

In 1987, six years after the first AIDS case in the US was noted, the CDC produced its first public service announcement about AIDS, “America Responds to AIDS” (National Prevention Information Network CDC, 2017). This was the first instance of information being widely distributed to the American public from a federal governmental source, not just the media. This campaign focused on reaching audiences from all walks of life, but some criticized that it didn’t reach the most at risk members of society. Peter Gould (1993) explained that even in 1990 the exact geography of the AIDS epidemic was still hidden away, due to reporting being done at a state, instead of a national level. Masking the geography of the AIDS epidemic helped to perpetuate the bias against people diagnosed with AIDS, especially in the urban areas. It also allowed for flawed reporting across the US.

In April of 1990, Ryan passed away from complications from a respiratory infection, exacerbated by AIDS. Ryan’s death prompted an outpouring of support for his mother, Jeanne. After his death, Jeanne, continued to spread information about AIDS and hemophilia to help educate the public (White-Ginder, ND). In August, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. This act provided federal funds for the HIV/AIDS community for continued research and treatment services. This was the first allocation of federal funds sent to help the communities affected by HIV/AIDS, before this act – AIDS was considered a state problem. Back in 1986, the Reagan administration cut federal funding for all social institutions including those related to helping AIDS patients (Patton, 1990). This severely

limited some states ability to care for its residents diagnosed with HIV/AIDS, due to lack of funds and resources. AIDS spread rapidly in the United States in the 1980's and 1990's, this was due, in part, to the lack of federal response to AIDS and many states inability to properly care for their increasing numbers of AIDS victims. The adoption of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, was integral in helping people diagnosed with AIDS throughout the United States receive the care they needed.

### THE MEDIA'S IMPACT ON AIDS

The media had an incredible influence on the diffusion of information about AIDS in the 1980's. In the early years of the epidemic, the media rarely reported on AIDS (Nelkin, 1991). When the media did report, it contributed to fear mongering about AIDS and the risk it posed. Patton (1990) also discussed that this media shift was no longer just large sensationalized AIDS stories that made it into the newspapers and into the evening news; there were new stories every day. Donovan (1993) explained that AIDS became the first 'living-room epidemic.' This epidemic was one the public watched closely as the disease spread and were fearful of it, despite knowing no one with the disease and having no real knowledge of AIDS. This idea of a 'living-room epidemic' allowed for the fear and unknown about AIDS to spread and grow throughout areas of the United States that had not yet encountered the disease first hand. The easily accessible news allowed for AIDS to become a topic in people's daily lives, even people who did not know anyone with AIDS. Nelkin (1991) explains that the media's response, or lack thereof, is part of what created the panic and oftentimes helped place the blame on gay

men and drug users. The dichotomy the media created between the different groups of AIDS victims, helped to shape the public and governmental response to the epidemic.

The first media source to cover Ryan's story was *The Kokomo Tribune*, the local paper, in March of 1985. This story discussed Ryan's struggle with returning to school after his diagnosis with AIDS. In September of 1985, Ryan appeared in his first National news story, when *USA Today* posted a photo of him in their "Newsmakers" section. Once Ryan was written about nationally, his fame began to grow exponentially. He was featured in an Italian television show in February 1986, and appeared on the *Today Show* and *CBS Morning Show* that same month. In April 1986, Ryan appeared on *The Tonight Show* and *Good Morning America* twice. In August of 1987, Ryan appeared on the cover of *People Magazine* for the first time, with the story entitled "Breaking America's Hearts." Ryan also had a TV movie produced about his life and diagnosis called *The Ryan White Story*. Over the next few years, Ryan was a guest on the *Phil Donahue Show*, on the cover of *People Magazine* for a second time, and a special edition of *LIFE* magazine.

The history of the AIDS epidemic in the United States and Ryan White's story in national media provided insight on the spatial distribution of the letters Ryan received. The continuously evolving public perception of AIDS is what makes Ryan's letters so significant in understanding the history and dichotomy of the groups of people diagnosed with AIDS in the United States. Poor federal response and lack of public information available made life difficult for people who were affected by AIDS.

## **METHODS & DATA**

The following methodology was used to determine the spatial and temporal distribution of the letters that were sent to Ryan White. The letters are part of the Ryan White Collection, which is housed at The Children's Museum of Indianapolis. It comprises of 5,379 of the letters Ryan received during his illness, as well as many letters of sympathy to his mother, Jeanne White-Ginder, after his death. The majority of the letters were received between 1989 and 1990. Jeanne White-Ginder, included most, but not all of the letters as part of the collection - an unknown number of letters remain in White-Ginder's possession. The collections staff at the Museum assume, based on conversations with White-Ginder, that fewer than 50 letters are housed outside of this collection. The withheld letters are mostly communications from celebrities and politicians, collections staff are working to temporarily accession these letters so they can be added to the digital archive housed by the museum. Examining the social and geographic context from which the letters were sent, allows for a better understanding of the reaction to AIDS in a child in the 1980's and 1990's. Since many letters appear to come from children around Ryan's age, it also shows how the youth of the United States reacted to another young person contracting AIDS.

The Indiana University Institutional Review Boards Office was contacted regarding this research. The data was kept on a secure external hard-drive and no individually identifiable data was used in the geocoding and other research processes. No individually identifiable data was made public and a permanent record was not maintained upon conclusion of the research.



The Children's Museum of Indianapolis began their digitization process of the letters in partnership with the IUPUI Center for Digital Scholarship in 2016. Each letter was digitally scanned and given a nine digit unique ID that is used to track the letter and the data connected to it. The redacted letters are housed online at <http://ulib.iupuidigital.org/cdm/search/collection/RyanWhite> and are available for public viewing. The letters were then coded with the associated metadata and that made the digital collection quantifiable. For this study, the museum provided the metadata that contained information on the letters Ryan received. The metadata, organized in twenty-four Excel spreadsheets, includes information on the sender, receiver (Ryan or his Mother, Jeanne), and keywords for each letter. The letter metadata was divided into twenty-four different excel documents, with no particular pattern. This was done so that multiple people would be able to record metadata at one time. Table 1 outlines the metadata categories.

Table 1: Metadata Categories

Column Title	Content of Column
Directory Name	9 Digit ID to Identify the Letters
Title	9 Digit ID to Identify the Letters
Sender (Full name)	Last Name, First Name
Sender	Name as signed on inside letter/note
Recipient (Full name)	Last Name, First Name
Recipient	Name as addressed on inside letter/note
Correspondence Note	Sent from City, State to City, State
Street Address of Sender	Street Address
City and State of Sender	City, State
Zip Code of Sender	Zip Code
Address of Sender	Combined Address of Sender - Address, City, State, Zip
Address of Recipient	Combined Address of Recipient - Address, City, State, Zip
Subject	Typically the Subject was "White, Ryan"
Genre	Correspondence, Greeting Card, Bookmarks, Photos, etc.
Geographic Location of Sender	City, County, State, Country
Physical Description	Count of the Contents (eg. 1 letter, 1 envelope, 1 photo)
Language	The letters all came in English
Date	Date of Postmark
Time Period	Broken in two time periods (1980-1989 & 1990-1999)
Source Collection	Ryan White Letters
Owning Institution	The Children's Museum of Indianapolis
Rights	<a href="http://rightsstatements.org/vocab/InC-EDU/1.0/">http://rightsstatements.org/vocab/InC-EDU/1.0/</a>
Usage Rights	<a href="http://www.ulib.iupui.edu/copyright">http://www.ulib.iupui.edu/copyright</a>
Type	Text, Still Image, Video
Item ID	10 Digit Code to Identify the Letters
Digital Specifications	Scanner: Bookeye 4V1; Archive view: 400 dpi tiff; Full view: 400 dpi JPG2000
Have Questions?	<a href="mailto:tcarchives@childrensmuseum.org">tcarchives@childrensmuseum.org</a>
Redaction level	Level of redaction needed on each letter.
Keyword	Categories and general comments about the letters

The first step of this analysis was to combine the Excel workbooks into one singular spreadsheet. This combined spreadsheet contained the collected metadata on the 5,379 letters that were given to the museum as part of the collection of Ryan's letters. The combined spreadsheet was then processed and consolidated in order to ready the data for analysis. Readyng the data for geocoding, which is the process of a Geographic

Information System (GIS) reading an address, and returning a point location on a map, was an integral step in this analysis. It gave spatiality to a flat data set. Ryan received 129 letters from outside of the United States, these addresses were excluded from the analysis. There were 776 records that did not contain any geographic reference data (e.g. empty cells or cells without an exact address), these were letters that were given to the museum without an envelope or did not have a return address written on the letter or envelope. The combined spreadsheet was then input into MapInfo, a Geographic Information System, and geocoded using the built-in US geocode tool. Geocoding the letters allowed for exact addresses to be located, so that more detailed analysis can be done.

Once the address for each letter was geocoded, Structured Query Language (SQL) was used to select letters on the State, County, Core Based Statistical Area (CBSA), and Zip Code levels. The governmental boundary data used was obtained in the form of TIGER Line Files from the United States Census Bureau. Using the generated SQL selections, Pivot Tables in Excel were used to create “count” fields for each boundary type, to summarize the number of letters in different geographies. Maps were then produced that demonstrate the count information in a thematic map based on the cartographic boundaries. The maps helped to provide visual explanation of the spatial distribution of the letters that Ryan received.

In order to investigate the socioeconomic and demographic profiles of the people who sent Ryan letters, 1990 Census data at the zip code level was used. 1990 was chosen as a baseline, since it was the first year the CDC released detailed data on the number of AIDS cases by state and metropolitan area, because it was a census year, and

because it fit well within the timeline of Ryan's letters. Using the demographic data allows for a characterization of the kinds of places from which the letters were sent. The demographics used were: total population, average household income, total number of households, ethnicity and race breakdowns, education level, and rural vs. urban population percentages. Each of these demographic categorizations informs the general sociodemographics of the places from whence the letters came. Total population and total number of households allowed for a comparison between the number of people and households, and the number of letters sent from each zip code. This helped to normalize the letter data to better understand where the density of letters sent was higher. The average household income allows for a look at how the people contained within each zip code fell on the low, middle, high income scale in 1990. Ethnicity and race breakdowns allowed for an examination of the different racial and ethnic breakdowns and how they compared to one another and Ryan's hometown. Rural vs. urban population breakdown showed how much of each zip code was made up of rural vs. urban area.

An expected value probability function was used at the state level to determine the estimated number of letters based on the 1990 state census population. This was used as a tool to compare the expected number of letters to the actual number of letters sent to Ryan, which allowed for an examination of the relationship between population and the number of letters he received. In order to calculate the expected probability function the number of letters sent and the total population in the United States were totaled. Then the total number of letters was divided by the total population to arrive at an average ratio. This ratio was multiplied by the state population to result in an expected number of letters based on a single states population. Given the state population, there were states that had

drastically more than the expected number of letters sent and there were states that sent fewer letters than would have been expected. Executing this function allowed for population to be used as a normalization factor that allowed for a deeper understanding of which areas sent letters at a higher rate per person.

Kernel Density Estimation (KDE) was then used to examine the distribution of the letters and to demonstrate where the letters came from in larger quantities. KDE calculates the density of features, allowing for hot spots to become visible. Using KDE allowed this research to view the letters on a continuous spectrum, without arbitrary political boundaries. The cell size selected was 0.025 square miles, this cell size was chosen in order to show the data as smooth and contiguous as possible. Natural breaks was chosen as the classification method, because it allows for like classes to be grouped together more effectively. Natural Breaks also helps to limit the in class differences, while spreading out the between class differences (Milic, et al., 2019). This showed the expanse of the spatial distribution in a new way, which helped display different ideas and allowed different conclusions to be drawn.

As part of the digitization process, the staff at The Children's Museum of Indianapolis, along with the team from the Center for Digital Scholarship at IUPUI, grouped letters into thematic categories by assigning keywords to each letter. Each letter can have multiple keywords assigned to it and thus it can fall into more than one category. The letters are broken down into ten categories that are grouped based on similarities: Fan Mail, HIV/AIDS, Quakery/Stalkery/Hate Mail, Religious, Ryan White Foundation/Donation, Ryan White Movie/Book, Letter/Card/Postcard/Pen Pal, Bullying/Discrimination/Death/Health Issues, Media Coverage/Celebrity, and

Condolences/Support/Sympathy. These categories allowed for an in-depth examination of how Ryan was viewed by the people who sent him letters.

In addition to their contents, a temporal analysis was done to examine how the number of letters Ryan received at a given time, related to what was happening in his life. A timeline displaying the volume of letters received by date helps to determine outside factors that may have influenced why Ryan received a greater or lesser number of letters. Using a temporal analysis of all the postmarked letters allowed for a better understanding of the timing of Ryan's popularity and fame. The first letter was received in January of 1980 and the last letter was received in November of 1993.

Following this methodology allowed for an interpretation of the geographic, social, and temporal context of the letters Ryan received. It helps illustrate how the people who sent Ryan letters viewed him, but it also exposed the complex response to AIDS and how this view shifted throughout the 1980's and early 1990's. This procedure allowed for an examination of the letters that were sent to Ryan.

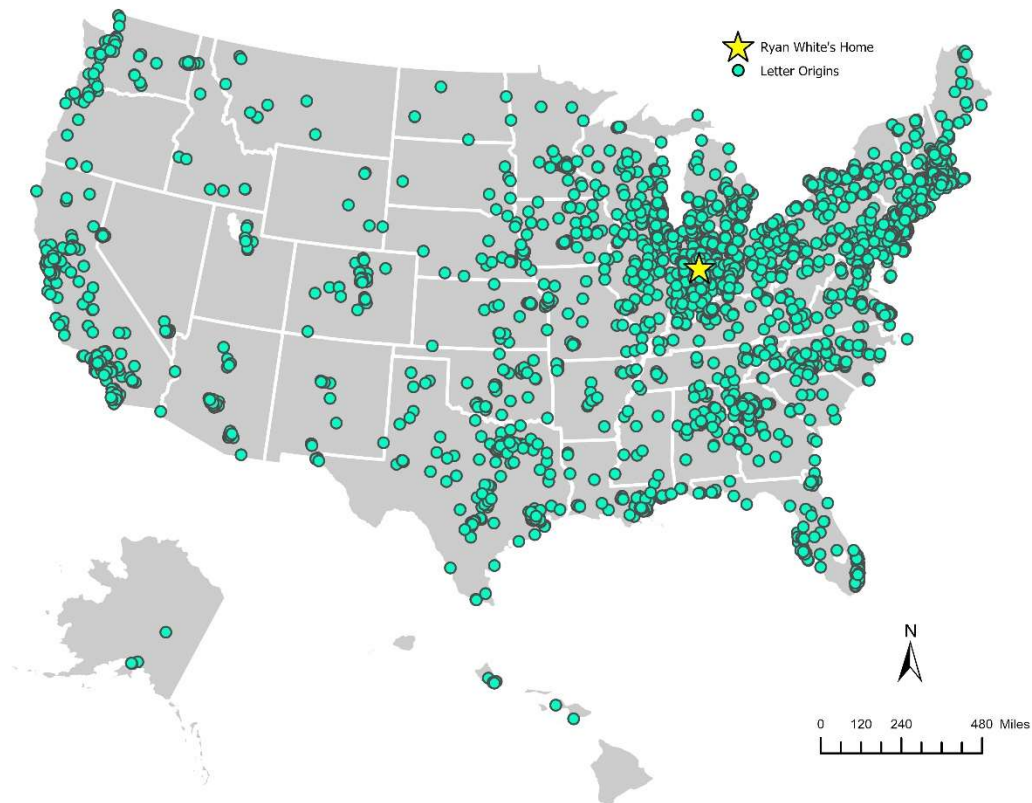
## RESULTS & DISCUSSION

Overall, the results of this research suggest that the letters display a map of sympathy for Ryan, as opposed to a map that reflected the spread of AIDS. Although this is a map that showcases sympathy for Ryan, it does not mean places with less letters didn't also feel sympathy. This just means that in this collection, those areas did not send as many letters. Per capita, more of Ryan's letters were sent from states in the Midwest, South, and New England area that had a relatively low number of AIDS cases. As demonstrated in their letters, the majority of Ryan's correspondents saw Ryan as "their victim" someone with whom they could see being their neighbor or friend. Ryan's correspondents saw him as an innocent victim, this was seen through the outpouring of sympathy and support for him and for his mother after his death.

One of the ethical issues that arose when working with this collection, came from the personal details people disclosed in their letters. When the letters were sent to Ryan, the writers weren't aware that this collection would one day be on display online and in a museum. The museum took rigorous steps to protect the identity of the letter writers, and it was important that this research do the same. When looking at the letters online (<http://ulib.iupuidigital.org/cdm/landingpage/collection/RyanWhite>) all personal information except for the first name and state of origin of the author has been redacted. Many letters mentioned health issues of the writer or members of the writers family. Keeping this personally identifiable information was of utmost importance to Museum and University staff. When geocoding the exact addresses of the letter writers I made sure to exclude the ID field, so that no one letter can be connected to any one point. This maintained anonymity, but also limited this research.

The MapInfo geocode tool was able to locate 3,947 exact addresses of the original 4,475. The geocode tool failed to locate approximately 12% of the addresses – the 528 that exact addresses that could not be located were a combination of PO Boxes, street name changes, and incorrect return addresses.

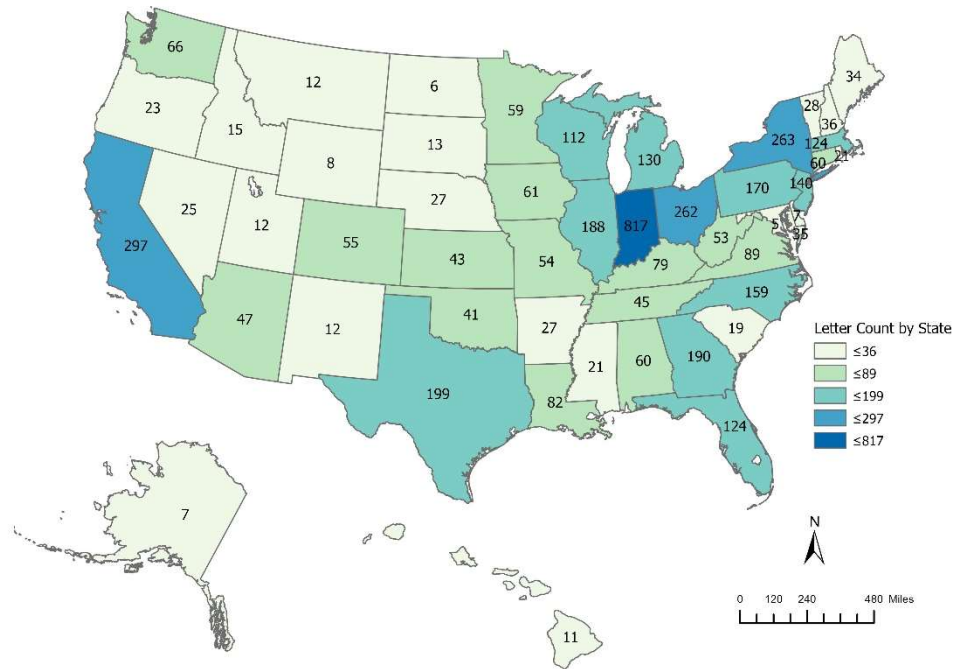
Map 1: Letter Origins



Map 1 displays the geocoded points from Ryan White's letters. Using the geocoded locations allowed for thematic maps to be produced that demonstrated the distributions of letters broken down by the governmental boundaries. These maps helped to reveal spatial patterns associated with the letters that Ryan White received.

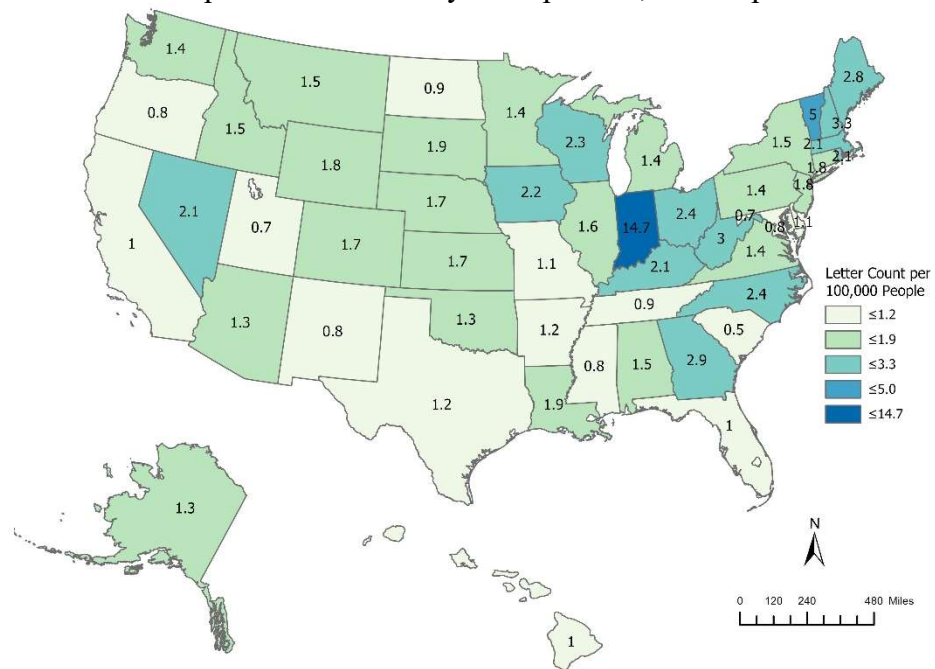


Map 2: Letter Count by State



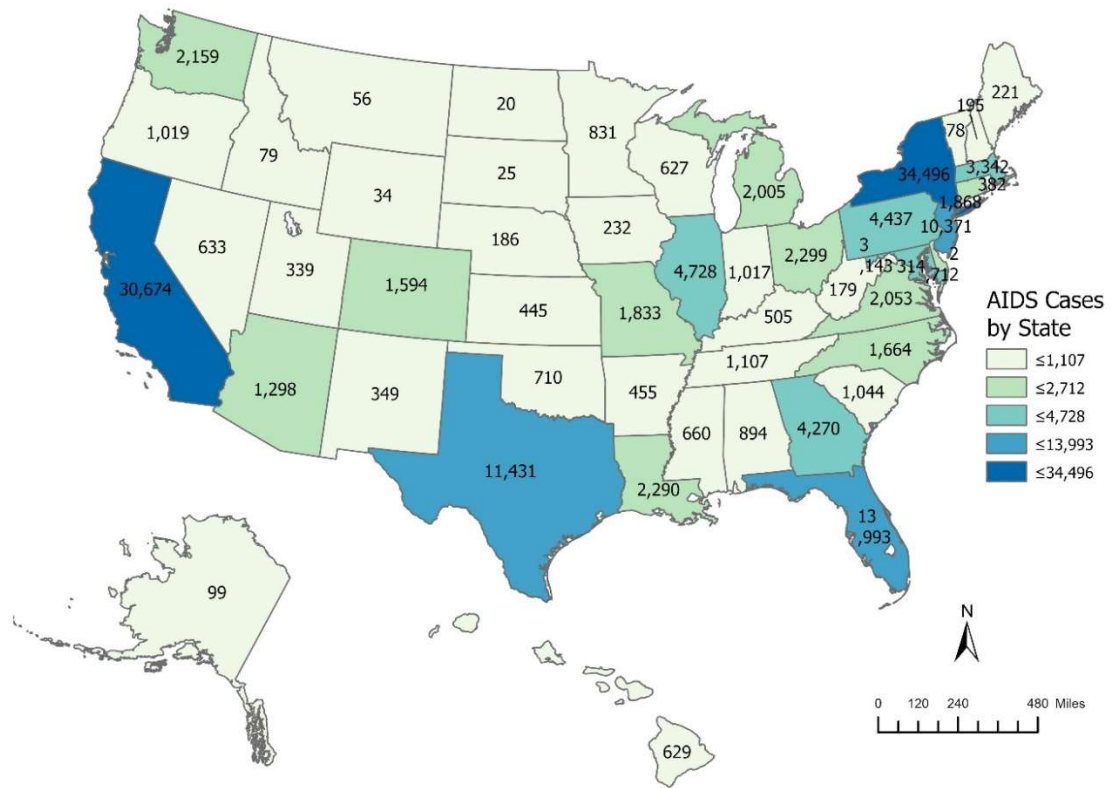
Map 2 demonstrates the raw letter count, by state, without any normalization factors used. This map was the starting point for better understanding what areas of the country could be considered outliers.

Map 3: Letter Count by State per 100,000 People



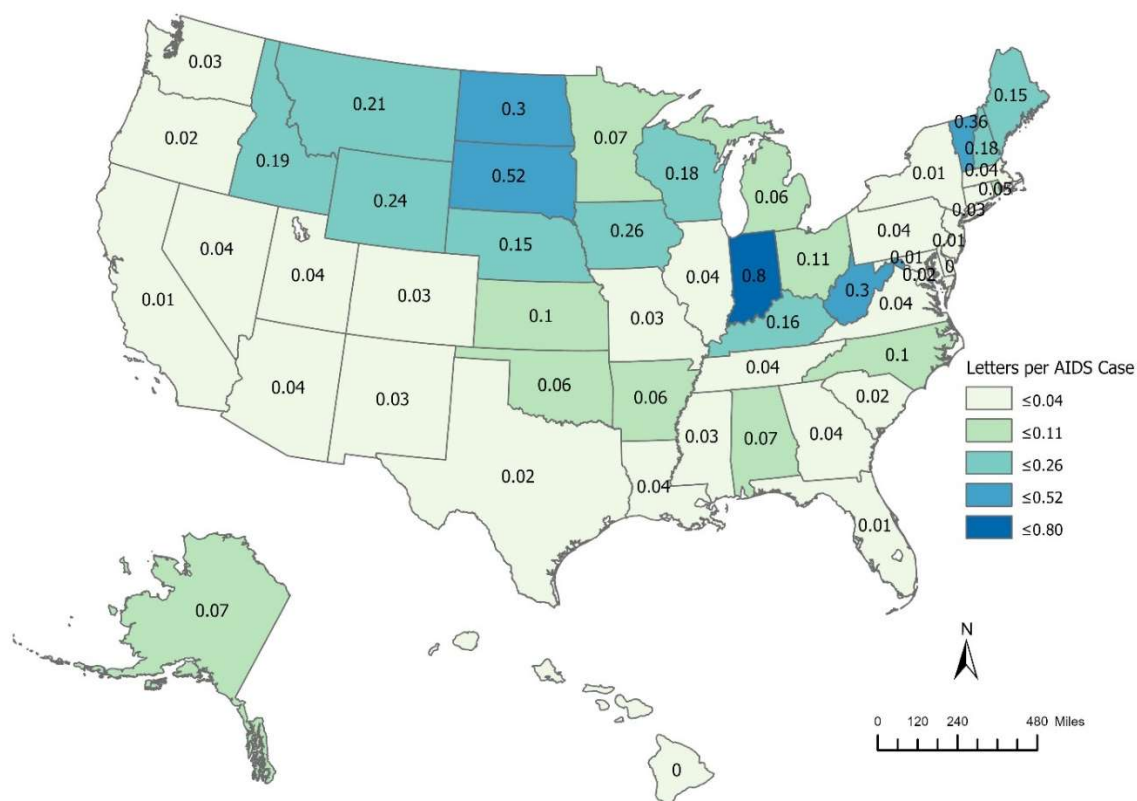
Map 3 demonstrates the number of letters sent, per 100,000 people. In Map 3 Indiana is still clearly ahead of the rest, despite its medium sized population. States with relatively low populations such as – Vermont, New Hampshire, Maine, Montana, Idaho, etc. show higher numbers of letters sent than some of the United States most densely populated states. These states include – California, New York, Florida, and Texas.

Map 4: AIDS Cases by State



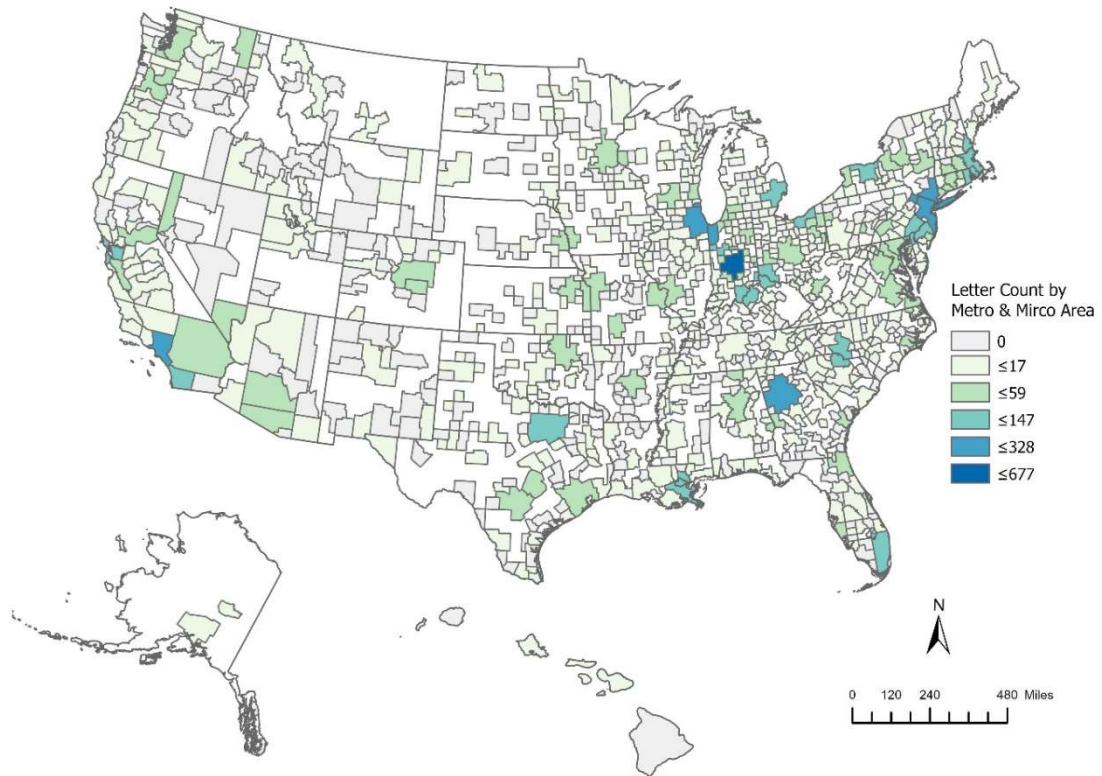
Map 4 shows the number of AIDS Cases in each state. The number of AIDS cases per state was found in the 1991 HIV/AIDS Surveillance Report produced by the CDC, which outlined the total number of cases in 1989 and 1990 across the United States.

Map 5: Letter per AIDS Case by State



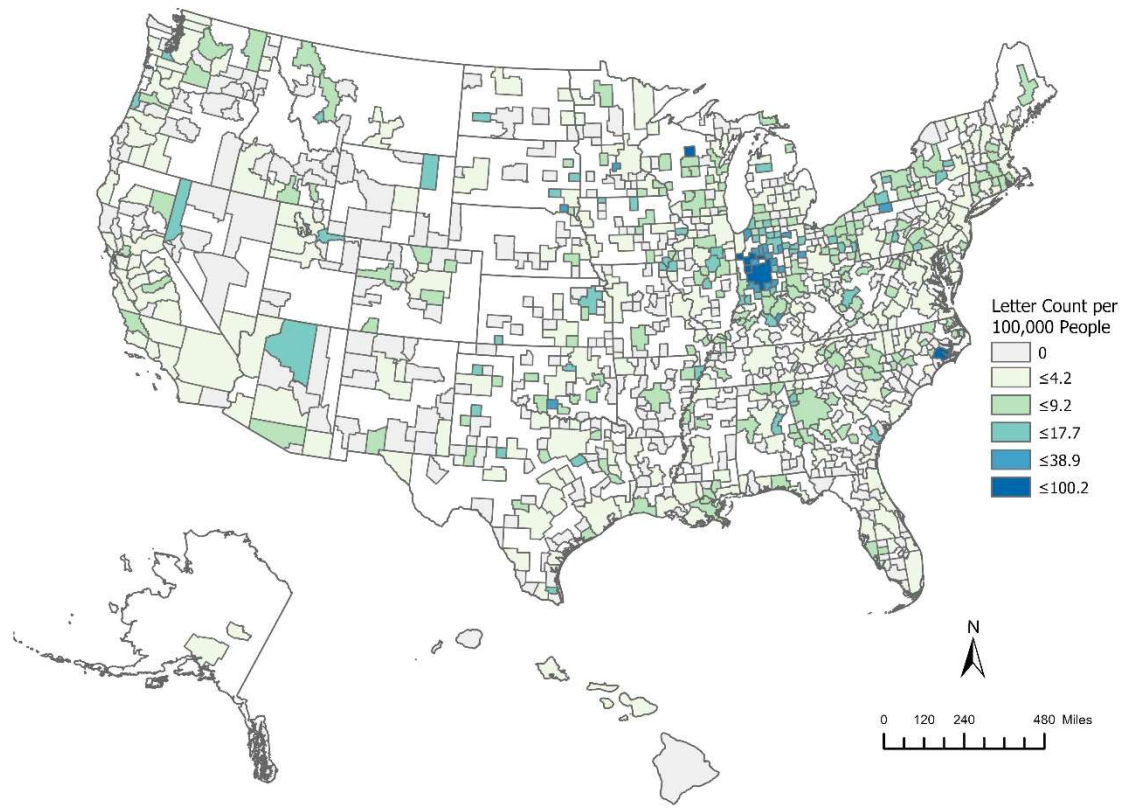
Map 5 displays that states with fewer AIDS cases seemed to have sent Ryan more letters. There are many assumptions as to why this may be the case. One thought is that the states with a higher number of AIDS cases focused their support and sympathy closer to home. Whereas in states with less AIDS cases, they may not have known someone who suffered from the disease, so they chose to support the child who became a national face of the AIDS epidemic.

Map 6: Letters by CBSA



Map 6 displays the number of letters by CBSA, also referred to as Metropolitan and Micropolitan areas, throughout the country. This map shows higher concentrations of letters in the Los Angeles, New York City, Chicago, and Atlanta areas, with lower numbers of letters coming from the less densely populated CSBA's. Map 6 shows a letter spread relatively close to a map of population, with more letters being sent from areas with higher populations. With the Indianapolis Metropolitan area having the largest number of letters sent, this is due not to the high population, but because Ryan was from Central Indiana.

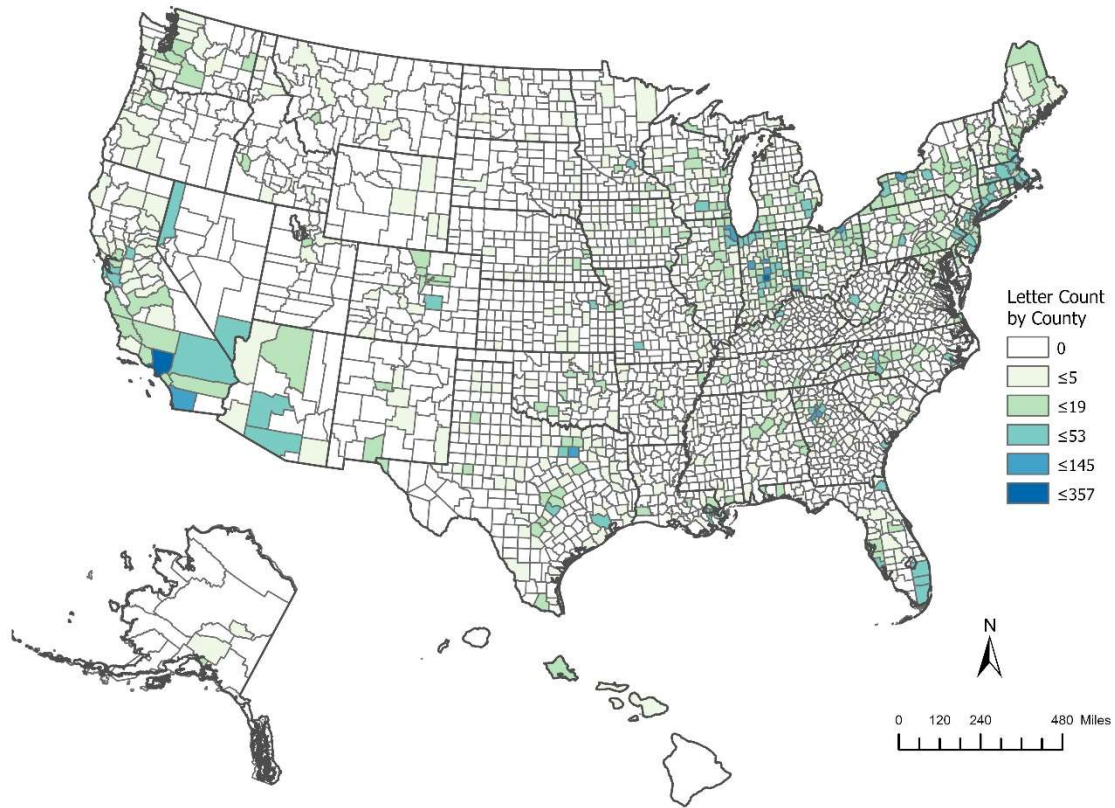
Map 7: Letters per 100,000 People by CBSA



Map 7 looks at the number of letters per 100,000 people. This map highlights where letters were being sent from at a higher rate. Some of the smaller CBSA's that show a high number of letters per 100,000 are Yankton, SD, Hutchinson, MN, New Bern, NC, Merrill, WI and many others. These CBSA's showed higher rates of letter sending per person than some of the United States most densely populated metropolitan areas. The metropolitan areas with the highest numbers of AIDS cases in 1989 and 1990 – New York, NY, Los Angeles, CA, San Francisco, CA, Washington DC, and Miami, FL – are some of the areas with the fewest number of letters being sent per person (CDC, 1991).



Map 8: Letters by County



Map 8 displays the number of letters sent by county, throughout the United States. This shows where letters came from on a finer grain, and allows for a more detailed understanding of the geography of this dataset.

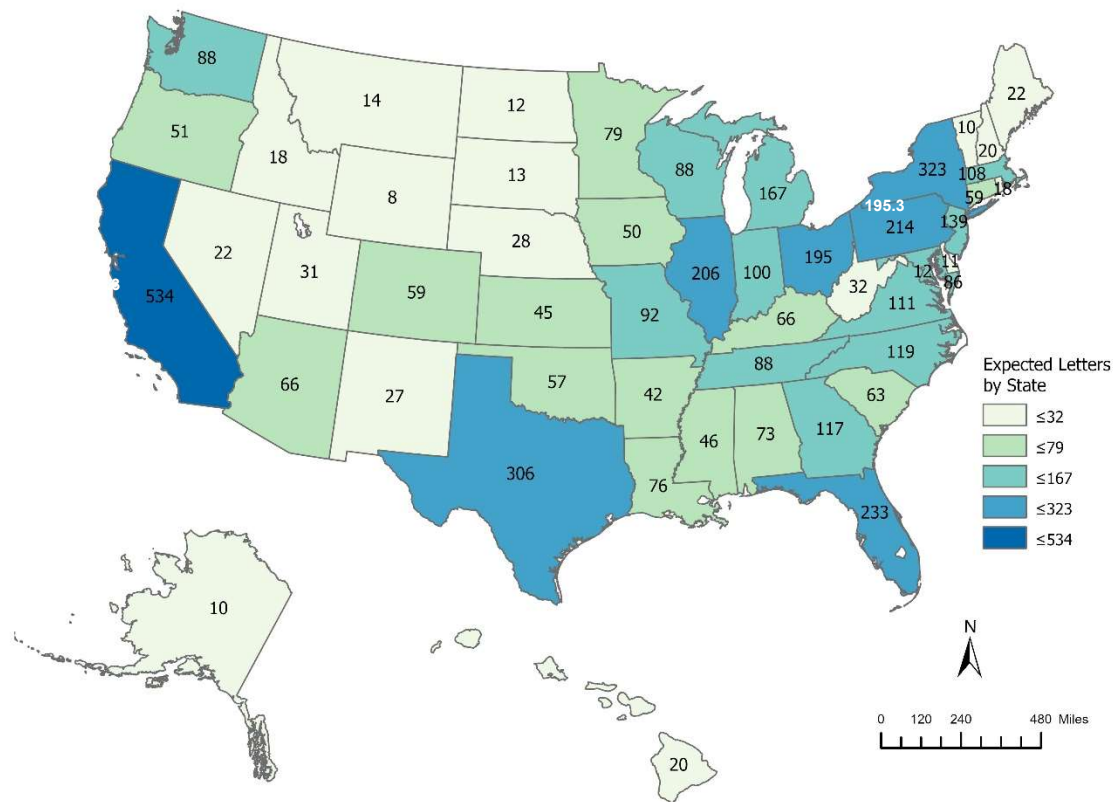
One issue faced when doing this research, is understanding if distance matters. Looking at this research from a postal distance perspective, it does not matter. It costs the same amount of money in postage to send a letter to the next county as it does to send one across the US. In relation to knowing about Ryan, distance can be seen as an important factor. Since the people closest to Ryan, especially those in and around Indiana were more likely to know about him, even though he received nationwide coverage. A distance calculation was used to determine the number of miles each letter travelled to make it from its origin to Ryan's home in Cicero, IN. Using this calculation allowed for

an understanding of how far these letters travelled and who sent them. The average number of miles the letters travelled was 598.8 miles to get to Ryan's home. The letter that travelled the farthest (4,344.2 miles) was from Pearl City, Hawaii. The letter that travelled the shortest distance (0.05 miles) came from right down the street from Ryan. Examining these two drastically different distances, helps to demonstrate how the idea of postal distance and absolute distance differ. Postal distance encompasses the whole world, or in this context – the United States, since letters could be sent for the same amount of money throughout the US. It essentially allows for anyone across the United States to have the same opportunity to send Ryan a letter, this is without consideration of socioeconomic factors that may have influenced access to letter writing materials or postage. Absolute distance refers to the amount of physical distance between Ryan and the person that wrote him a letter, the person just down the street could have walked the letter to Ryan, but chose to mail it. For this analysis, I viewed distance as a relative factor, since the people closest to Ryan were more likely to have heard about his condition, especially before he became national news. By the time most of the letters were received, Ryan was national and international news, but socially, people closer in distance may feel more apt or comfortable to show their support. In this analysis, I determined that distance did not seem to be an important factor in determining who wrote Ryan letters. This is why population was chosen as a normalization factor, as opposed to distance.

An expected value probability analysis was completed in order to better understand which states sent more or fewer letters to Ryan than would be expected, based on population. This analysis displayed that overall, the number of letters were not

predictive of the state population. There were states that had drastically more than the expected number of letters sent and there were states with fewer letters than would have been expected, based on population. Indiana had the largest number of letters sent, I believe this was due to the fact that Ryan was from Indiana.

Map 9: Expected Letter by State



Map 9 shows the expected number of letters based on population, this adheres to a map of population. Showing states like California and New York, to have a much high letter sending potential than states with smaller populations.



Table 2: Expected Probability Results

State	Letter Count	1990 Population	Expected	Difference
California	297	29,676,302	534	-237
Florida	124	12,931,635	233	-109
Texas	199	16,974,076	306	-107
New York	263	17,945,408	323	-60
Maryland	35	4,767,061	86	-51
South Carolina	19	3,485,914	63	-44
Pennsylvania	170	11,868,174	214	-44
Tennessee	45	4,876,405	88	-43
Missouri	54	5,112,329	92	-38
Michigan	130	9,286,474	167	-37
Oregon	23	2,841,519	51	-28
Mississippi	21	2,573,177	46	-25
Virginia	89	6,184,425	111	-22
Washington	66	4,862,623	88	-22
Minnesota	59	4,370,052	79	-20
Utah	12	1,722,059	31	-19
Arizona	47	3,662,839	66	-19
Illinois	188	11,427,840	206	-18
Oklahoma	41	3,145,076	57	-16
New Mexico	12	1,515,052	27	-15
Arkansas	27	2,347,556	42	-15
Alabama	60	4,040,583	73	-13
Hawaii	11	1,108,030	20	-9
District of Columbia	5	606,897	11	-6
North Dakota	6	638,795	12	-6
Delaware	7	664,547	12	-5
Colorado	55	3,292,032	59	-4
Idaho	15	1,005,210	18	-3
Alaska	7	549,763	10	-3
Montana	12	797,972	14	-2
Kansas	43	2,476,453	45	-2
Nebraska	27	1,577,459	28	-1
Wyoming	8	453,587	8	0
South Dakota	13	696,000	13	0

Table 2: Expected Probability Results Continued

State	Letter Count	1990 Population	Expected	Difference
Connecticut	60	3,284,702	59	1
New Jersey	140	7,723,894	139	1
Rhode Island	21	999,920	18	3
Nevada	25	1,200,354	22	3
Louisiana	82	4,207,722	76	6
Iowa	61	2,775,492	50	11
Maine	34	1,227,928	22	12
Kentucky	79	3,683,901	66	13
Massachusetts	124	6,013,758	108	16
New Hampshire	36	1,104,110	20	16
Vermont	28	562,762	10	18
West Virginia	53	1,793,480	32	21
Wisconsin	112	4,889,798	88	24
North Carolina	159	6,626,110	119	40
Ohio	262	10,845,228	195	67
Georgia	190	6,476,858	117	73
Indiana	817	5,542,990	100	717

Map 10: Actual Letters minus Expected Letters by State

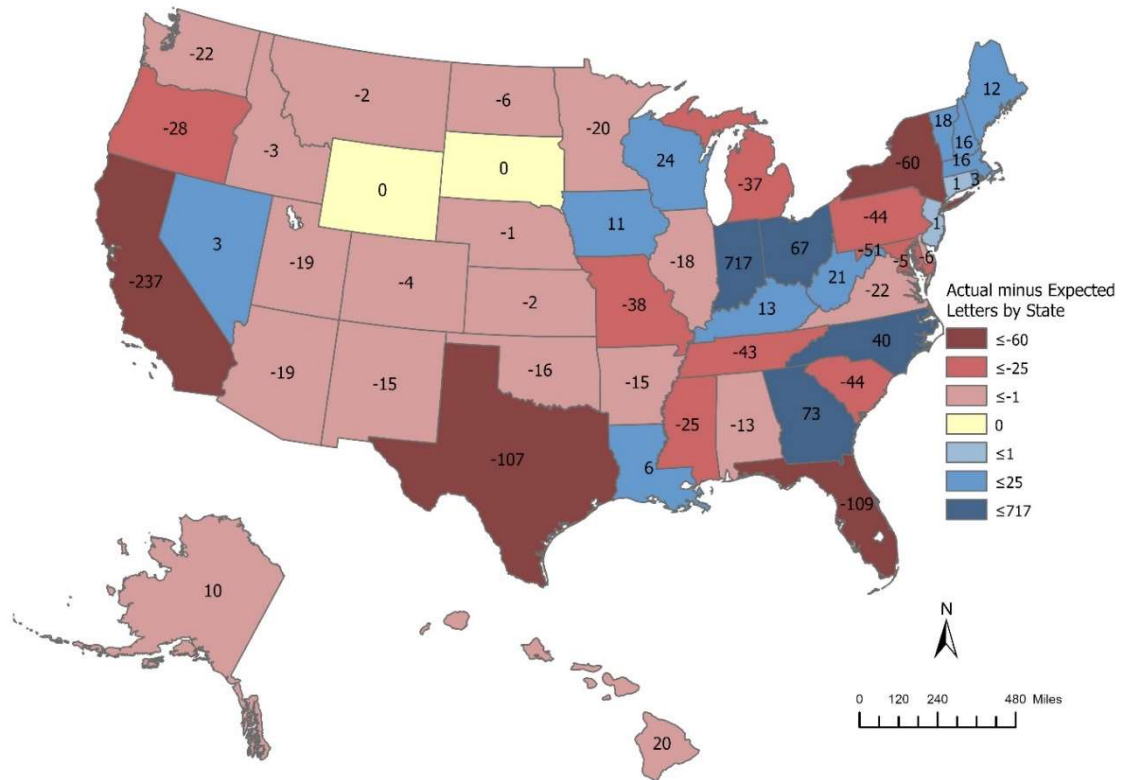
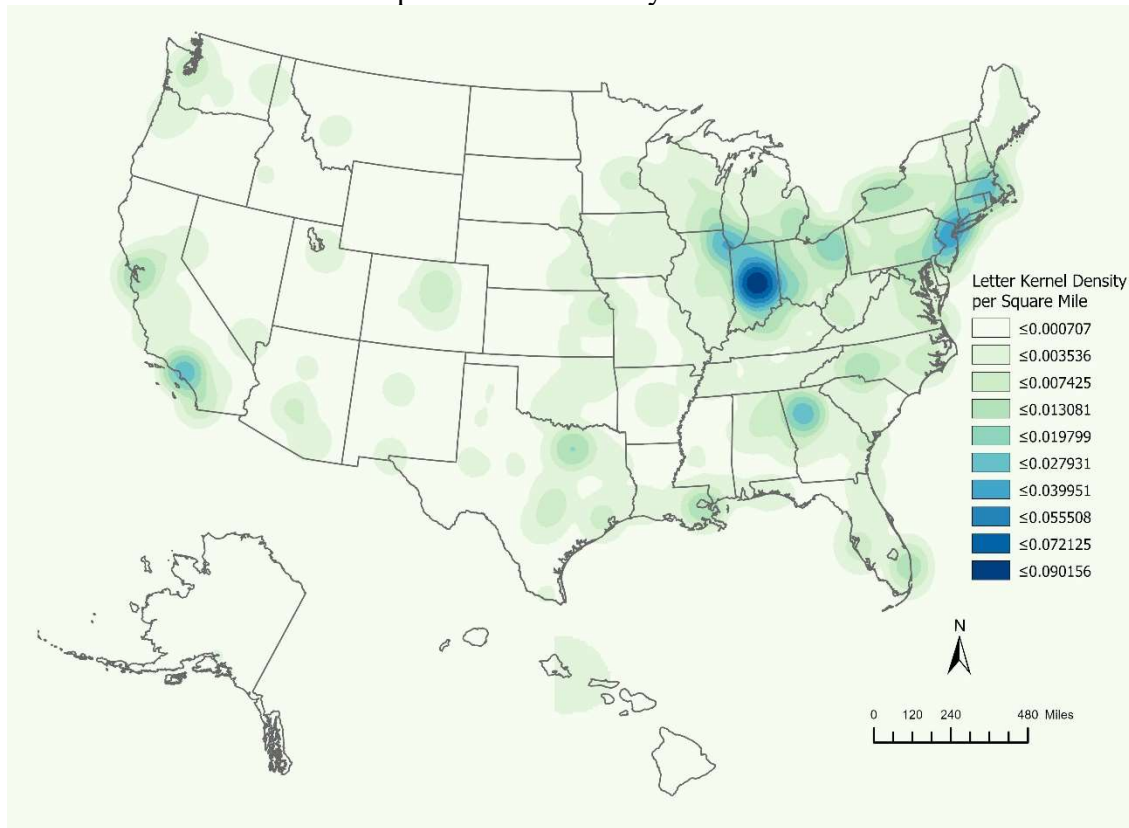


Table 2 and Map 10 showcase the states with higher and lower than expected number of letters. The map demonstrates where people may have been more or less likely to send letters in support of Ryan. The highest concentration of letters came from the Midwest – with Indiana, Ohio, Wisconsin, and Iowa showing more letters than would be expected based on population. The area that showed the next largest number of overages came from the South - particularly Kentucky, West Virginia, North Carolina, and Georgia. But the South also had states that showed drastically fewer than expected letters – particularly Texas and Florida. California and New York, although across the country from one another were dealing with the AIDS epidemic front and center, joining with Texas and Florida these states had the highest AIDS rates per 100,000 people in 1990 (CDC, 1991).

One inference made from the expected value probability function was people living and dealing with the AIDS epidemic close to home, were less likely to be support Ryan. Since Ryan was from Indiana, it makes sense that the largest number of letters would come from his home state and surrounding states. The most interesting outlier is the states in New England, in which each state had a surplus of letters sent.

The demographics used were obtained from the United States Census Bureau, and showed that no one type of person sent Ryan a letter. Ryan received letters from some of the largest cities and smallest towns throughout the United States. On average, Ryan's correspondents lived in places that were approximately 70% urban, 86% white, with an average household income of approximately \$38,000, and college educated. Since many of the letters sent to Ryan seem to have been sent by children and teenagers the demographics are more representative of their parents, but none-the-less are a valuable part of the interpretation.

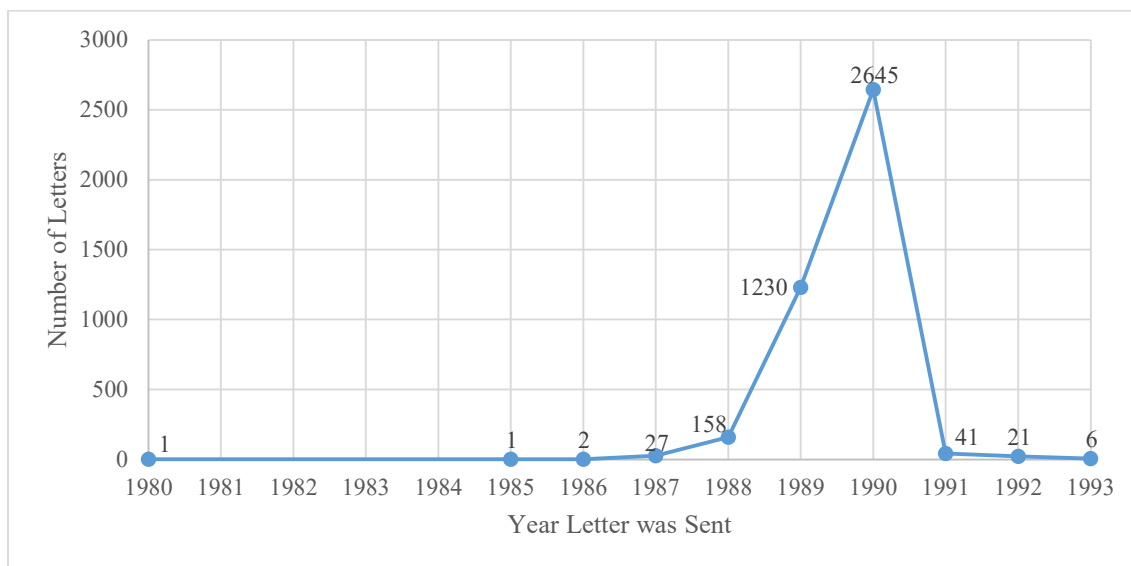
Map 11: Kernel Density Estimation



Map 11 illustrates the Kernel Density Estimation which allowed for the letter density to be viewed on a continuous basis. This showed that the number of letters throughout the country varied. Central Indiana has a “bullseye effect” that shows the highest density of letters sent. The most letters sent were from Central Indiana, showing that on average 0.09 letters were sent from a single square mile

A temporal analysis of all the postmarked letters allowed for a better understanding of the letter contents and the timing of Ryan’s popularity and fame. Although this displays a large breadth of time, there was only one letter received in 1980 and 1985, and two letters in 1986. The majority (3,875) of the letters were sent in 1989 and 1990. This is believed to be because Ryan’s mother began keeping the majority of the letters Ryan received, instead of just letters she deemed special, as in previous years.

Figure 1: Letters Sent by Year



A further examination of the temporal distribution allowed for and understanding on whether or not the media had an effect on the timing of the letters Ryan received. The three years I focused on for this analysis are 1988, 1989, and 1990 since the collection has the largest number of letters sent during this timeframe, as well as many of Ryan's media appearances happened during the last three years of his life.

Figure 2: Number of Letters Sent by Month-Year

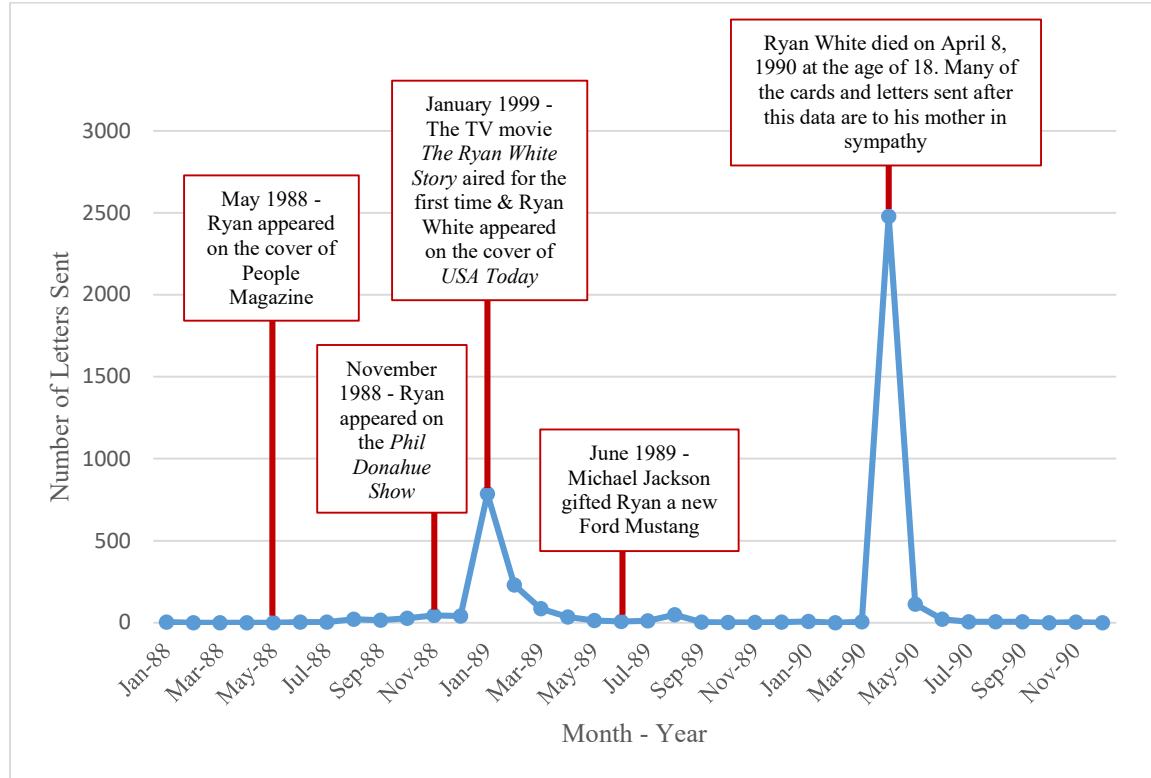


Figure 2 above shows the month to month distribution of the letters housed by the Children’s Museum, that Ryan White received. It shows that when Ryan had large media events, it often precipitated a sending of more letters. The two most notable spikes are when *The Ryan White Movie* came out on television, and again when Ryan passed away. The letters sent after Ryan had passed, were often in the form of condolences to his mother and family.

Examining the letters that Ryan received on a subject level, allowed for an understanding of why the letters were sent. Everything from sympathy about his diagnosis, fan mail from girls his age who thought he was cute, other people who were diagnosed with AIDS or knew someone who was diagnosed, and hate mail. Doing a category analysis allowed for a deeper understanding of the motivation behind the letters.

Figure 3: Letter Category Analysis

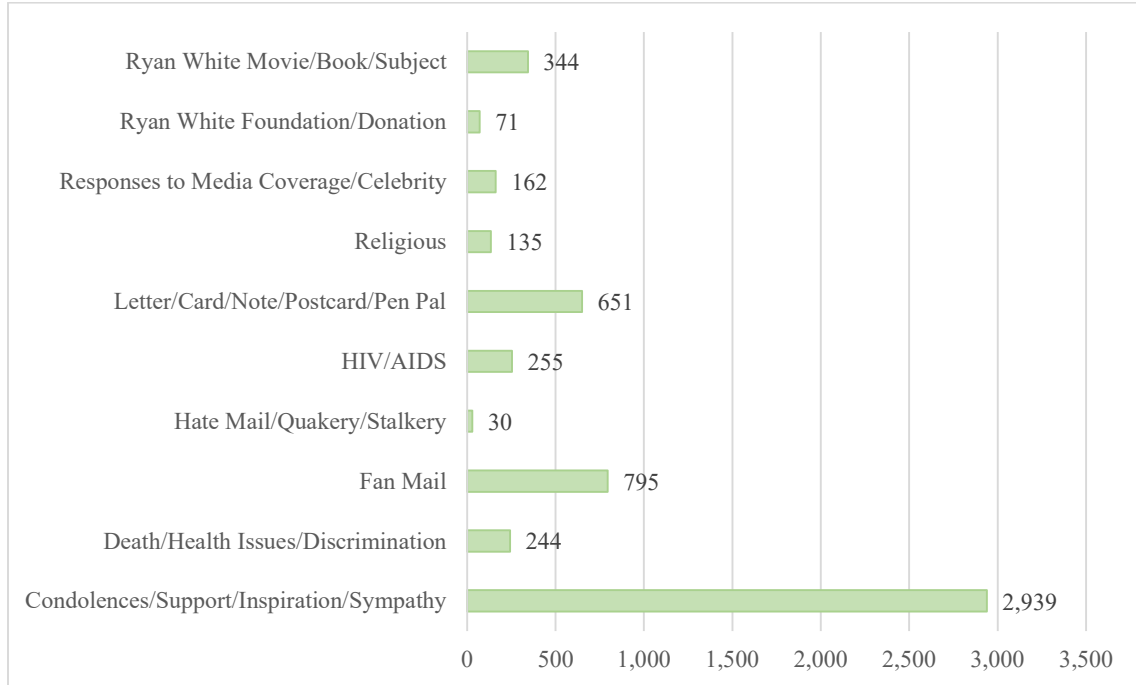


Figure 3 showcases the many different reasons that people sent letters to Ryan and his mother, Jeanne. The largest category was Condolences/Support/Sympathy at 2,939 letters, this category contained letters that showed general sympathy for Ryan and his diagnosis, as well as for his mother after Ryan's death. The smallest category was Hate Mail/Quakery/Stalkery with only 30 letters, these letters ranged from outright hate mail, to someone claiming they had the cure for AIDS. This difference shows how Ryan was perceived by the people who sent him letters, it also could be conceived that his mother did not keep mean or hateful letters, which could be why this category appears so small.

Taking both the subject and temporal analysis into account allowed for a broader understanding of the different subjects and how Ryan's life events effected the number that were received. The temporal analysis showed that 1,838 letters were sent after



Ryan's death in April of 1990 – these mostly fell into the largest category of Condolences/Sympathy/Inspiration/Support.

Understanding the social and geographic framework of these letters was the goal of this research, examining the above results allowed for an in depth look into the people who sent Ryan letters. This bettered the understanding of this collection and the motivations behind sending Ryan a letter.

## **LIMITATIONS**

There were many limitations throughout this research, the most notable being that this is not a complete collection. It represents a small portion of the letters Ryan received over the course of his life. This is not a survey of the United States response to Ryan White, merely a sample of people who chose to write letters. Another limitation was the need to keep the sender information separate from the geocoded data points, this limited the number of connections that could be made from the point locations to the metadata. For example, a keyword by geographic location or a spatiotemporal analysis could not be done because of this disconnect.

## **FUTURE STUDY**

The Children's Museum of Indianapolis and the IUPUI Center for Digital Scholarship are continuing to work on digitally transcribing the letters. This would give future researchers a way to examine letter contents with their spatial distribution, and see if any patterns emerged.

## **CONCLUSION**

The correspondence Ryan received is representative of the era and the response to AIDS in patients with hemophilia but is not representative of the response to gay men or drug-users who were diagnosed with AIDS. I also believe that there is more research that can be done with the idea of postal space and how much socioeconomic status influenced who knew about Ryan and had the means to send him letters.

Examining these letters allowed for a better understanding of how Ryan was viewed throughout the United States. It also allowed for an investigation of the spatial distribution of the letters and how this plays a role in the public perception of Ryan in the 1980's and 1990's. Using geographical investigation, temporal analysis, and a density examination allowed for Ryan's letters to be placed in their social and geographic context.

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## **CURRICULUM VITAE**

**Haley Lynn Shaeffer**

### **Education**

- Master of Science in Geographic Information Science from Indiana University, earned at Indiana University-Purdue University of Indianapolis – May 2020
- Bachelor of Arts in Anthropology from Indiana University, earned at Indiana University-Purdue University Indianapolis – May 2016
- Undergraduate Certificate in Geographic Information Science from Indiana University, earned at Indiana University-Purdue University Indianapolis – May 2016

### **Professional Experience**

Simon Property Group

October 2017 – April 2020 | Indianapolis, IN

Real Estate Research Analyst (October 2017 – April 2020)

- Support Leasing and Development by creating exhibits that showcase properties to potential tenants.
- Maintain proprietary databases using Excel, Access, MapInfo, and PowerBI.
- Perform retailer specific research by creating maps, comparing demographics, and examining overlap.
- Create customer trade areas for each Simon center using third party ZIP code level customer location data.

Real Estate Research Intern (February 2017 – October 2017)

- Learn market information specific to each Simon Center.
- Use MapInfo and Trade Area Systems to create maps and procure data upon request.

IUPUI Department of Geography

July 2015 – May 2018 | Indianapolis, IN

Graduate Research Assistant for Dr. Daniel Johnson (August 2016 – May 2018)

- Examine the metadata for the 5,300 letters sent to Ryan White from across the world.
- Interpret the patterns of the letters sent using geographic, social, and temporal information.
- Create maps using ArcMap and ArcGIS Pro that give a visual explanation of the research conclusions.

Undergraduate Research Assistant for Dr. Daniel Johnson (July 2015 – July 2016)

- Recreate an archaeological site throughout time using ArcMap, ArcScene, 3D scanning processes, and drone technology.
- Catalog, identify, and describe artifacts in Excel database.

IUPUI Department of Anthropology

January 2016 – May 2016 | Indianapolis, IN

Undergraduate Research Assistant for Dr. Susan Hyatt

- Utilized Mappler and ESRI Story Maps in conjunction with Ethnographic Methods to produce a project on the Mapleton-Fall Creek Neighborhood.
- Worked alongside students in the Ethnographic Methods course to collect and analyze data needed for the final project.

### **Notable Projects**

US Forest Service – Hoosier National Forest

March 2017 – May 2017 | Bedford, IN

Buffalo Trace Trail – Hoosier National Forest

- Completed a cost-distance analysis to recreate the least cost path and compare it to the suspected trail.

IUPUI Anthropology Department and the Department of Natural Resources

November 2016 – January 2017 | Indianapolis, IN

Charles C. Deam Wilderness Area

- Analyzed the Charles C. Deam Wilderness Area using slope and raster calculations in ArcMap to create a map of possible archaeological site locations that was to be used in precursory survey work.

Midwest Archeological Conference Poster Presentation

October 2016 | Iowa City, IA

*A Geospatial Analysis of Mississippian Period Travel and Organization in the Central Illinois River Valley* by Haley Hoernschemeyer, B.A., William Burcham, and Jeremy Wilson Ph.D.

- Utilized cost-distance analysis to recreate the most likely travel routes between Mississippian Period Villages in the Central Illinois River Valley.